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RadioMe: challenges during the development of a real time tool to support People with Dementia

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Dementia is a neurodegenerative disease which is progressive in nature. The symptoms worsen over time, leading to the deterioration of the patient's quality of life as well as their caregivers. Being diagnosed with dementia means losing one's own independence. There is no cure for such disease and its degree of progressiveness is variable. From a certain point on Persons with Dementia (PwD) need the presence of somebody that surveils their actions and needs. However, in the early phases of the disease, this need for person support is not permanent. The existence of Assistive Technologies (AT) can alert caregivers for these needs, giving much more freedom both for the patients and caregivers. Major challenges, however, exist for HCI researchers in designing ATs for PwD. Four challenges will be highlighted and discussed in this paper, and can be considered by other HCI researchers during design and development stages: 1) the stigma of being frail and old, and its consequences for HCI researchers, 2) technical, ethical, and legal issues with available smart devices, 3) lack of availability of database with annotated stress bio-signals from PwD, and 4) access to PwD in times of Covid-19. These challenges became evident during the development of the RadioMe system which aims to deliver a prototype aid that remixes a radio stream in real-time incorporating agitation reduction and reminders.

CCS Concepts: • **Human-centered computing** → **Collaborative and social computing devices**; **Accessibility Technologies**.

Additional Key Words and Phrases: assistive technologies, smart-home devices, wearable sensors, challenges, persons with dementia, independent living,

1 INTRODUCTION

Aging is the main factor that will shape the future of a vast majority of nations [10]. The combination of a longer life and decreasing fertility rates shift demographics from the once 'normal' distribution of many young people and few older people to a population that has more 50+ year olds than children [10]. Europe already has more older people than children, and will have twice the number of older people than children in 2050 [15]. Developing countries such as China and Brazil are faced with an ever increasing older population [15], with nearly 140 million over 60 in China [10]. The

United Nations estimate that by 2045 [21] the number of people over 60 will exceed the number of people younger than 15 - a historical first in humankind.

The unprecedented rate of aging demands societies to reshape many aspects of daily life [10]. More attention to health care and disease management is required, as well as more innovation is necessary to maintain quality of life and decrease costs imposed on healthcare systems.

With the increase in population of older adults worldwide, the number of Persons with Dementia (PwD) has also increased significantly [19]. The World Health Organisation (WHO) describes dementia a syndrome which is progressive in nature and affects memory, thinking, and cognitive abilities to perform activities of the daily life [19]. It is estimated that 50 million people live with dementia worldwide, and there are nearly 10 million new cases every year [20].

Similar to healthy older adults, PwD prefer to age in a familiar environment such as their own home [9]. However, with the progression of dementia, PwD face substantial challenges adapting to their physical, psychological, and social environments [2]. Additionally, ageing in one's own home comes with its own challenges such as loneliness, social isolation, and impaired mobility [26]. Dementia as well as ageing threaten PwDs to be displaced into non-preferred caring facilities [27].

Assistive Technologies (ATs) are promising agents in facilitating ageing-in-place for a growing number of cognitively impaired older adults [18]. ATs have been shown to support independent living [8], enhance well-being [6], and therefore promote ageing in a familiar environment [17, 18].

With the decrease in multi-generation living and the increase in nuclear families worldwide [14] innovative solutions can support and encourage independence, decision making, and communication [27] for PwD. If designed well, ATs have the potential to increase quality of life in PwD and alleviate the burden of families caring for lone-living PwD [6].

This position paper argues for the integration and extension of existing assistive systems (e.g. Amazon Alexa, smart watches) into the lives and homes of PwD, whilst highlighting challenges which come with this decision. It will further introduce and discuss the aims of the RadioMe project which will deliver a prototype aid that remixes a radio stream in real time incorporating 1) agitation reduction and 2) reminders.

2 BACKGROUND

Trends in assistive technologies provide HCI researchers with a multitude of devices to support ageing-in-place for PwD; a few examples are a) assistive robots (assistance in daily activities, communications, and social connectedness) [27], b) wearable and non-wearble sensors (e.g. gait and fall detection) [11], and 3) intelligent smart-home applications (e.g. Amazon Alexa, Google Home Hub) [4].

Wearbale sensors such as smart watches are an affordable and stigma-free way [12] of monitoring PwD's bio-signals. They can come with various pre-installed applications (e.g. fall detection) which allow general physicians and primary care givers to monitor PwD's health and offer a way of detecting health risks (e.g. data analytics) [1]. Nowadays, smart watches come with stress detection functionalities (e.g. measurements of heart rate, body temperature). Stress and agitation detection is crucial in PwD as agitated PwD can harm themselves and others. However, agitation detection in itself is not enough to support lone-living PwD; agitation intervention is necessary. Music has been shown in meta-studies to decrease arousal [22], facilitate blood pressure recovery [7], reduce anxiety [24] and aid psychophysiological recovery from stress [23]. It can be difficult for PwD to operate devices to play such interventional music, particularly when most needed.

As listening to the radio is common in the age range of PwD [25], the RadioMe system will use this medium for agitation intervention and reminders by mapping music elements onto the radio stream. The radio provides an interface involving voice and music, and one that is familiar to PwD. Market research has shown that older people are more likely to own smart-home applications

such as Amazon Alexa and Google with 33% aged 55 and over [13]. As the main usage of these
smart-home devices is streaming music and the radio (71%) [13], they can be optimal tools for
the RadioMe system. These devices are tested for usability, robustness, and are generally visually
pleasant. And as ATs can be operationalised for multiple purposes, there might be less age-related
stigma as opposed to purpose specific tools. It is very important to PwD that other people do not
perceive them as old and sick [5]. Turning a device that is already sitting in people's homes into
AT can have a positive impact on the lives of PwD. As Amazon Alexa and Google Hub come with
developer APIs, which allow the installation of custom software, it is possible to repurpose these
smart-home devices for the RadioMe project and play interventional music when most needed.
However, there are major challenges we face in the development of the RadioMe project.

3 CHALLENGES

3.1 Lack of Openly Available, Annotated Stress Data from PwD

To the best of our knowledge, there is no database openly available with annotated stress bio-signals
from PwD. We understand that due to ethical implications and contract constraints, researchers
might not be allowed to share data. However, this lack of data poses an obstacle as other research
groups are tasked with collecting stress data from PwD themselves. Collecting and annotating data
from a pool of PwD is not a trivial task, very time consuming (potentially months of work), and
requires the help of care givers. This issue is further aggravated by the current Covid-19 pandemic
which renders physical access to vulnerable people such as PwD almost impossible.

3.2 Ethical and Legal Issues around Smart Devices

For PwD to accept a wearable sensor on their bodies, their purpose cannot be mainly an AT. The
perceived loss of independence and stigma around ATs prevents PwD from feeling comfortable
with these single-purpose devices which leads to abandonment of the tool. If an AT is to be worn
successfully it should be in the form of a device which is acceptable to wear on the body for the
majority of the day, i.e. a wrist watch [5, 12]. Readily available smart watches (e.g. Garmin, Apple
watch) provide a wide range of bio-signal data, are water proof, robust, comfortable, and their
appearance can generally be customised to the preference of the wearer.

An unexpected challenge we encountered was the availability of wearable sensors that provide an
interface for real-time data processing as well as are affordable (e.g. Garmin's application developer
fee is $40,000). Most smart watches come with their own cloud-based eco-systems (e.g. Garmin,
Apple watch) where user data can be accessed through an API. However, this results in lags of
potentially up to several hours as upload does not always happen immediately and most often,
the wearer of the watch needs to issue the upload manually. A core requirement for the RadioMe
system is agitation detection and intervention. A PwD's transition into agitation requires immediate
intervention and therefore is a time critical event. Continuous, real-time access to data is imperative
for the success of agitation detection and reduction. As these watches synchronise the data in the
cloud via smart phone applications, it is further required that a smart phone is continuously carried
on the user's body. It is not realistic to expect PwD to carry two devices on their body at all times.
Therefore, a large portion of available smart watches is not appropriate for our purposes.

There are smart watch Operating systems (OS) that allow installation of custom applications
and thus the synchronisation of the data with a nearby server. In pilot tests, open source OS
were found to either cause non-negligible discomfort when wearing (e.g. BangleJS) or lack basic
functionalities such as a properly working bluetooth connectivity (e.g. WaspOS). Google Wear
OS is an operating system that allows the implementation of custom applications, is integrated in
various smart watches from multiple brands, and thus allows the wearer to choose a wrist watch

according to their personal preferences. However, Wear OS watches impose major ethical concerns as it is not clear what data and how much data processing is happening on the servers. Irrespective of operating system and device (e.g. Google or Amazon) there are several issues that might be flagged by a sponsorship/ethics committee:

- will any personal identifiable be stored there (note that these companies are renowned for collecting data in the background which might be problematic).
- what data will the device collect outside of the custom application? What will the OS be able to access?
- who's Google/Amazon account will be used? Universities generally have policies about storing data on university accounts only.
- researchers are not allowed to set up accounts on people's behalf (against T&Cs), which poses the question of who will have responsible for managing, deleting the data.

The same ethical and legal concerns apply to the usage of smart-home devices. However, these come with additional privacy concerns (e.g. the perception that any spoken word is recorded) [16].

4   DISCUSSIONS AND CONCLUSION

This paper introduced the Radiome project which aims to deliver a prototype aid that remixes the radio in real-time for people with mild to moderate dementia who live alone, incorporating agitation reduction, and reminders. We argue that already available Assistive Technologies should be used when designing smart-home interfaces for Persons with Dementia, however, we are aware of multiple challenges to the integration of AT into dementia care. Despite the challenges we discussed in this paper, we believe that researchers should aim to reuse AT that are in people's households, rather than developing and integrating single purpose devices into PwD's lives. Producing single-purpose research prototypes might hinder their future usage as maintenance support might cease with the end of the research project. If the research outcome, however, is incorporated into a multi functional smart-home appliance, it might have a longer shelf life.

The concept of the RadioMe system can be applied across cultures as listening to the radio is an international past-time activity for older people. On average, listening to the radio constitutes 12.3% of daily media consumption worldwide, with stark differences between regions [3]. In Central and Eastern Europe for instance 29% of daily media content was consumed through the radio. Whereas in Pacific Asia 5.3% of consumed media content through the radio (21% in Latin America, 18.4% in North America, 20.5% in Western Europe, and 18.2% in the rest of the world) [3]. Despite ever increasing video content, the radio's usage remained stable over the last decade. A decline in radio consumption is not predicted for the near future [3] nor its replacement through television and on-demand streaming content. However, the applicability of the RadioMe system across borders might be limited due to software restrictions in certain countries (e.g. Google in China), and ethical and legal concerns regarding data collection.

5   CONCLUSION

The CHI 2021 workshop on "Designing Interactions for the Ageing Populations – Addressing Global Challenges" will provide a great opportunity to discuss the challenges mentioned in this paper, as well as whether and how research outcomes can be applied across borders.

6   ACKNOWLEDGEMENTS

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